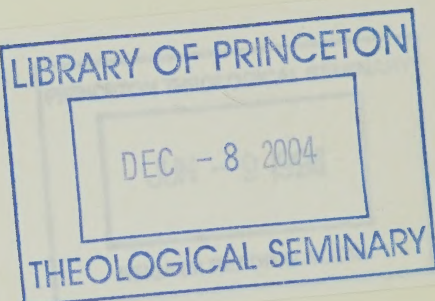


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**MANUAL
FOR PASTORAL
CARE**

PS

**RONALD H.
SUNDERLAND
AND
EARL E. SHELPS**



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AIDS, a Manual for Pastoral Care

Ronald H. Sunderland
and Earl B. Shelp



The Westminster Press
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AIDS, a Manual for Pastoral Care

Ronald H. Sunderland
and Earl E. Shelp



The Westminster Press
Philadelphia

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1

AIDS—The Medical Facts

Early in 1981, a group of Southern Californian physicians reported a growing incidence of a then rare form of pneumonia, *Pneumocystis carinii* (PCP), in a group of gay males.¹ The report received little attention until, later in 1981, a number of cases of a rare form of cancer, Kaposi's sarcoma (KS), was reported in a group of homosexual males in New York.² *Pneumocystis carinii* pneumonia is considered "opportunistic": that is, it tends to occur in people whose immune systems are compromised, as a result of poor nutrition or medical treatment, for example. Patients placed on immunosuppressive drugs following an organ transplant, in order to inhibit rejection of the transplanted organ, may develop a malignant disease, the most common being one of the lymphomas or Kaposi's sarcoma. Kaposi's sarcoma appears most commonly as purplish, irregularly shaped blotches on the skin and mucous membranes and is rarely fatal. The appearance of PCP and KS in gay males focused attention on an emerging hypothesis linking certain infections and malignancies to immune function.

During the early 1980s, the number of people with either KS or PCP increased rapidly. Other cancers and opportunistic infections were added to a list of complications of immune dysfunction that pointed to an as yet unnamed disease.³ Epidemiological studies indicated an infectious organism, probably viral, as the cause, and the name acquired immune deficiency syndrome (AIDS) was given to this new phenomenon. It was termed a "syndrome" because of the presence of a variety of signs and symptoms.

Evidence indicated that the organism was blood-borne and could be spread by sexual contact. One fact became clear: most of those infected were young, male homosexuals whose average age was 32 years. As more data were gathered, the groups at risk expanded: intravenous drug abusers, hemophiliacs, recipients of blood transfusions, and recent immigrants from Haiti.

Two salient features of this new phenomenon emerged during 1982. First, it was confirmed that young gay males constituted the predominant population. Second, all infected people showed evidence of compromised immune systems, particularly in the set of lymphocytes called T cells and more specifically in the helper T₄ cell subset. Other abnormalities were identified in the B cells, or antibody-producing lymphocytes, in the ratio of helper T cells to suppressor T cells, in other cells of the cellular immune system known as macrophages, and in the absolute number of helper T cells. These immune-compromised patients were unable to ward off potent opportunistic infections and certain cancers. They were also susceptible to a wide range of infections caused by fungi, bacteria, protozoa, and other viruses. Their immune systems appeared to be unable to cope with the sudden and catastrophic onslaught.

Investigations into these phenomena were proceeding in the United States and in France. In 1983, scientists at the Pasteur Institute in Paris isolated a virus, named lymphadenopathy virus (LAV), which belongs to a class of viruses termed retroviruses. Unable to produce large amounts of the virus because no suitable culture existed for the purpose, their discovery went largely unrecognized. In 1984, a similar virus was isolated both at the National Institutes of Health and in a San Francisco laboratory. With the availability of the necessary culture in which to grow the organism, investigation into its characteristics was now possible. It quickly became apparent that the virus, variously named human T-lymphotropic virus (HTLV-III), lymphadenopathy associated virus (LAV), and AIDS-related virus (ARV), seemed preferentially to infect the helper T cells of immunologically active lymphocytes.⁴ It is the abnormal functioning of these cells that constitutes the core of the catastrophe which results from the activity of the AIDS

virus, now universally termed the human immunodeficiency virus (HIV).⁵

HIV and Immune Dysfunction

It is important to recognize that the non-neurological manifestations of acquired immune deficiency syndrome are not caused by HIV; the virus is not itself the source of the infections or malignancies that result from the immunological impairment. Researchers believe that many people who become infected by HIV will not progress to full-blown AIDS. This may be because a variety of co-factors may contribute to the ability of the virus to disable the immune system. Inadequate nutrition, use of recreational drugs, improper rest and exercise, previous infectious history, and other lifestyle factors are believed to increase the likelihood that HIV infection will result in clinical illness. Since many of these factors are avoidable, the chances of preventing the disease by self-discipline are increased.

Infection occurs when HIV attacks the body's cellular immune system.⁶ The immune system, located primarily in the white blood cells, consists of a number of interrelated cells which, when their activity is coordinated by the helper-inducer subset of T lymphocytes, seek out, isolate, and destroy invading organisms. The analogy of "invasion" and "search-and-destroy mission" is apt. An invading infectious agent is first identified by sentries—macrophages—which notify the helper T cells that the body is under attack. The helper T cells activate the immune system, consisting of killer T cells, beta cells, and phagocytes, which attack the invading microbes. When the infection has been controlled, suppressor T cells instruct the helper T cells that the battle has been won. The helper T cells withdraw the defending cells, and the immune system is placed on hold until the next infection is detected.

The impact of HIV is profoundly different from that of other infective agents. The viral attack on the helper T cells renders them incapable of alerting and activating the immune system. This may lead to what is perceived at present to be an irreversible immune dysfunction. It is as if the enemy's first offensive action is to take prisoner the

entire command structure of the defending forces. While isolated defense units will be able to function for some time without the coordinating direction of the command post, it is only a matter of time until the isolated defense units are tracked down and rendered ineffective. The virus's attack on the helper T cells is a worst case scenario. It enters the one kind of cell that can mobilize the defense forces and incorporates itself there, permanently changing the nature of the T cell. When the cell dies, reproduced viruses are released to invade additional helper T cells. In short, the T cells become factories for turning out more HIV. To return to the military analogy, the invading agents don the uniform of the defense forces and, as saboteurs, enhance the invaders' purposes.

HIV can also infect other cells: for example, those of the central nervous system (CNS).⁷ The impact on the CNS is critical, since once a neurological cell is destroyed it cannot regenerate itself. In addition, the so-called blood-brain barrier (the physiological screen in the brain's blood supply) allows certain microorganisms, like HIV, to cross into the CNS but does not permit coarser substances, such as potential antiviral drugs, to pass through. Therefore, the likelihood of countering the virus with therapeutic agents remains unknown. Infection of the CNS by the AIDS virus often results in distressing and permanent dementia, cognitive impairment, and paralysis.

There is evidence that once the helper T cells have been infected, the individual is likely to remain a carrier of the virus indefinitely and is assumed to be capable of transmitting the virus to others, while perhaps not developing full-blown AIDS. It also seems clear that, following infection of a person, the virus may remain dormant within the immune system for an extended period. Scientists are reluctant to identify an upper limit and fear the period may extend beyond ten years.

Symptoms of Infection

Symptoms of AIDS include fungi in the oral cavity, persistent fever, unexplained weight loss, fatigue, heavy night sweats, mild to extreme diarrhea, lymphadenopathy

(swollen lymph nodes in two or more areas other than the groin area), and a variety of neurological deficits. Purple or reddish blotches or bumps may appear on the skin or mucous membranes, indicating KS. There may be a deterioration in vision and the appearance of spots before the eyes. Infection of the respiratory system may be indicated by a persistent dry cough, with or without shortness of breath, not apparently due to smoking. Diffuse aches and pains of the muscles and joints and persistent headaches are also indicative of HIV.

Definition of AIDS

The Centers for Disease Control (CDC) in Atlanta initially adopted narrow criteria for reporting AIDS. A person was identified as having AIDS only if manifesting Kaposi's sarcoma or PCP after previously being in good health. In 1983, AIDS was described as a reliably diagnosed disease that is at least moderately indicative of an underlying cellular immunodeficiency. That is, the key to diagnosing AIDS was immune deficiency. By 1986, the CDC's classification system of HIV infections has been expanded but the definition of AIDS remains relatively narrow: diagnosis of an AIDS-related malignancy and/or one or more "opportunistic infections."

Opportunistic Infections

The body is host to many germs which under normal conditions are rendered harmless by the immune system. If the immune system is impaired, these usually harmless germs may become killers. These life-threatening infections include: PCP, toxoplasmosis (a protozoan infection of the brain), cryptococcus (a fungus that attacks the lungs, CNS, lymph nodes, gastrointestinal tract, and bone marrow), cryptosporidium (a protozoan infection leading to chronic diarrhea), herpes simplex (a virus that infects the skin and mucous membranes), and cytomegalovirus (a virus that attacks lungs, CNS, GI tract, and urinary tract). These infections are the most common immediate cause of death in

AIDS patients. Among the more common cancers that arise as consequences of infection by HIV are KS, Hodgkin's disease, and other cancers of the mouth, throat, and lymph system.

A person with AIDS may develop an opportunistic infection, recover with the aid of medication, but experience recurring, increasingly acute levels of infection, each leaving the patient weakened and still less able to throw off other infections. The progression of infection and recurring illness often results in loss of control over basic functions and daily activities.

Clinical Tests for HIV Infection

Blood tests are commonly used to determine if a person is infected by HIV.⁸ A sequence of tests is used to screen blood. First is the ELISA, an extremely sensitive test that will react positively to the presence of antibodies to the virus in almost all cases. Even this test, however, has its limits. It appears that a threshold of up to six months exists beyond which the test is activated. If the infection is very recent, antibody levels may not be high enough to activate the test, leading to a "false negative" reading. On the other hand, factors other than the AIDS virus may trip the test, leading to a "false positive" reading. If a positive result occurs, a second ELISA test is given. Finally, to confirm two positive readings on the ELISA test, the Western blot test, more sensitive than the ELISA, is used.

AIDS-Related Complex

It is variously estimated that 40 to 50 percent of infected individuals will develop AIDS within five years following infection, and an additional 25 percent will develop AIDS-related complex (ARC). ARC is a constellation of indications, manifested by people infected by HIV, which degenerate into chronic conditions. They include heavy night sweats, swollen glands, fever, unexplained weight loss, diarrhea, fatigue, and perhaps a series of nonopportunistic

infections. Chronic lymphadenopathy syndrome (LAS) is manifested by swollen glands in areas other than the groin over a period of three months or longer. It is estimated that one tenth of the patients with this infection will develop full-blown AIDS.

Researchers initially thought ARC patients would not develop fatal illnesses, but that finding has been qualified, as some ARC patients are dying without progressing to full-blown AIDS. The proportion of ARC patients who will eventually develop AIDS is still uncertain. People with ARC face a number of factors that greatly exacerbate their condition. Infected with HIV, they are infectious and sick. But since their symptoms do not fit the precise definition of AIDS, they are excluded from the CDC's cumulative total of people with AIDS and also from some of the benefits, including the disability status accorded people with AIDS. Despite the rapid expansion of knowledge of HIV and its consequences, new phenomena continue to appear, and its impact is steadily increasing. Because some doctors probably are underreporting the disease, and because there are still many unknown factors, the final scope of this catastrophe is yet to be known. Figure 1 depicts current estimates of the epidemic in the United States.

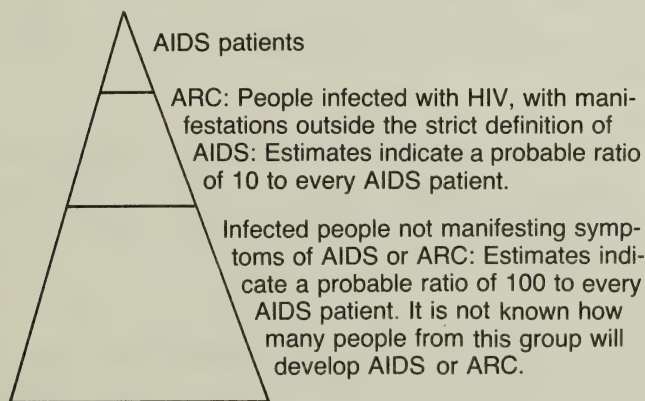


Figure 1

Routes of Infection

HIV is a blood-borne virus. It has been isolated in the blood, semen, vaginal secretions, saliva, and tears of infected people. Yet HIV is not spread easily. It is not carried in the air or in water and cannot be spread, for example, by coughing, insect bites, or contaminated drinking vessels. The CDC reports that, for infection to occur, the virus must have direct entry into the bloodstream. It *may* be transmitted during sexual intercourse (vaginal or anal) via certain mucous membranes or skin abrasions. Use of a contaminated needle, usually by an intravenous drug abuser, accounts for the growing number of addicts who have developed AIDS. AIDS may also result from use of blood or blood products in surgery or in the care of hemophiliacs. Children born to mothers with HIV may be infected by blood exchange through the umbilical cord or during passage through the birth canal.

Patient Populations

Homosexual males currently constitute the largest group of people with AIDS in the United States. The rate of increase among gay and bisexual men is falling, due to behavior modification, and the rate of increase among heterosexual men and women is accelerating. The following estimates were released by the U.S. Public Health Service on June 6, 1986:⁹

Twenty to 30 percent of the estimated 1 to 1.5 million Americans infected with HIV as of June 1986 are projected to develop AIDS by the end of 1991. The latency period between infection and overt AIDS averages 4 or more years in adults; therefore, most persons who will develop AIDS between 1986 and 1991 will be those who are already infected with HIV.

Based on an empirical model that uses reported cases of AIDS, by the end of 1991, the cumulative cases of AIDS in the U.S. meeting the CDC surveillance definition will total more than 270,000. During 1991 alone, more than 145,000 cases of AIDS will require medical care and over 54,000 AIDS patients are

predicted to die, bringing the cumulative number of deaths due to AIDS to over 179,000.

The empirical model may underestimate by at least 20 percent the serious morbidity and mortality attributable to AIDS, because of underreporting or underascertainment of cases.

In 1985, 9,000 cases of AIDS were diagnosed in the United States and reported to the Centers for Disease Control. The empirical model predicts that cases will continue to increase through 1991, that there will be nearly 16,000 cases reported in 1986, and more than 74,000 cases projected for 1991. The estimates for 1991 range from 46,000 to 90,000.

More than 70 percent of the cases will be diagnosed among homosexual or bisexual men, and 25 percent of the cases will occur among IV drug abusers with some overlap to continue between the groups. Because the periods between infection and disease are long and variable, cases will continue to be reported among transfusion recipients and persons with hemophilia.

Additional cases in heterosexual men and women are projected; the 1,100 (7 percent of the total) for 1986 will increase to nearly 7,000 (more than 9 percent) by 1991. This group includes patients who reported heterosexual contact with an infected person or someone in a risk group, as well as cases in groups in which epidemiologic studies suggest heterosexual transmission as the major risk factor. By 1991, more than 3,000 cases will have been diagnosed in infants and children.

The AIDS virus probably originated in central Africa and is very similar to a virus found in African green monkeys. It is believed that the virus passed to Haiti through Haitians who had been in Africa, into the Caribbean basin, and from there to Americans vacationing in Haiti. In a very short time it spread throughout the world. Research in Zaire, Ruanda, and Uganda indicates that the incidence of the disease is much higher in those countries than in Western countries. Further, transmission by heterosexual intercourse is prevalent. Zaire's male-to-female ratio is 1:1, whereas in the United States fewer than 1 in 10 AIDS

patients are women. There is also great concern because of the high level of infection in African children. It is impossible to be precise about the situation in Africa because of the lack of data and the limited health care facilities, which restrict diagnosis and treatment of AIDS patients.¹⁰

Life Expectancy and Treatment

Currently, patients with full-blown AIDS have a mortality rate of 80 percent at two years, approaching 100 percent after four years.

Conventional therapies exist for the treatment of complications arising from the underlying immune disorder, including many of the opportunistic infections and some of the malignancies. Unfortunately, the treatment for complications and symptoms of CNS disorders related to AIDS remains mostly symptomatic. Further, not all of the infections and malignancies secondary to AIDS are manageable by conventional therapies. The sense of powerlessness felt by physicians and researchers is most acute with regard to the underlying dysfunction of the immune system. At present, there are no cures, but several compounds appear to be palliative: for example, AZT¹¹ and ribavirin. Medical scientists believe that an effective fight against AIDS will require the discovery or development of an antiviral drug to rid the body of the causative agent, followed by therapies designed to bolster the immune response if the body fails to do so itself. Thus, at present, the fight against the spread of AIDS is best undertaken by educating all people to protect themselves against infection and to modify their high-risk practices in order to reduce the likelihood of new infections. Basic scientific research is directed toward the development of a vaccine.¹² Clinical trials of such a vaccine will begin in 1987, but it is much too early to estimate whether these efforts will produce effective and safe results.

Psychosocial Issues¹³

People with AIDS range over the whole spectrum of social groups, age, and occupations and, of course, include men, women, and children. While most are young adult

gay males, not all people with AIDS live in the fast lane, and they are often professionals, holding responsible jobs and with a strong desire to continue in full employment. Many members of the gay community have chosen not to reveal their lifestyles to their families, especially to parents. Parents of a person with AIDS thus may discover both facts at the same time, leading to a situation of stress and grief. It has been our experience that few members of this population regret their gay lifestyle, and most have sought to protect their parents by not disclosing it. Just at the time when they need strong emotional and physical support, they often must deal with their health crisis under the most adverse conditions.

At the same time, very specific questions relating to future care must be resolved. Patients must make legal decisions. Who will be given power of attorney? Will a living will be prepared? Who will take care of the patient when the patient is unable to do so? In addition to legal issues, questions of insurability arise. If an employer terminates the employment of a person with AIDS, health insurance as well as income may be lost. All these aspects of this catastrophe have a critical impact upon the person's self-image and sense of security. The need for emotional and often religious support calls for a compassionate response from the religious community.

2

Confronting the Reality of AIDS

The discovery that one carries AIDS antigens evokes an immediate and pervasive sense of threat. Personal and family stability, the wider network of relationships, professional hopes and dreams, and ultimately life itself are threatened with extinction. The crisis of discovery often leads to a breakdown of previous coping structures. As the person comes to terms with the new reality, measures are taken to deal with it, but because it is difficult to cope with AIDS, many people may be altogether unable to adapt. Anxiety may remain diffuse, but it is likely to evoke specific fears related to the presence of AIDS antigens: fear of infection and impairment, fear of uncertainty, fear of stigmatization and ostracism, fear of sexuality, and fear of death.

Fear of Infection and Impairment

Most people take health, or "wellness," so much for granted that the onset of an illness is usually accompanied by denial. Considerable pain and discomfort may be tolerated and carefully hidden from a spouse. Explicit symptoms may be discounted, with an offhand "It's nothing; it will pass in a day or two." A woman with a small breast mass may defer an appointment with her physician for months. A busy executive or a union organizer may ignore tightening chest pains, passing them off as indigestion, while consuming large amounts of antacid tablets. In part, the explanation may be that to admit illness is to acknowledge a sense of inferiority to the general healthy community. A more likely explanation probably lies in the

fact that to become unwell is to cross a barrier that raises the specter of one's mortality. In her article "Stigmatized Health Conditions," Joan Ablon¹ refers to the condition of ill health as a deviant state, defined by Talcott Parsons as a socially deviant status in relation to institutionalized social expectations, sentiments, and sanctions. Parsons² includes in his description the notion that the state of ill health is itself undesirable and carries an obligation to get well. Ablon suggests that the sick person is reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribution is a stigma. Therefore, sickness, in our health-obsessed society, is to be avoided at all costs, and manufacturers of all types of health care products play upon the fear of infection.

One of the first consequences of illness is some measure of social isolation. Even in the most stable families, where every effort is made to reassure the patient, sickness is characterized by physical separation, either to the bedroom or to the hospital. Such physical separation, however, portends an even more acute fear. Infection, physical impairment, heart attack, and stroke, no matter how successfully the patient or "victim" is able to thrust the event from conscious consideration, carry an image of a brush with death that raises ultimate questions of existence and its termination. As a person becomes aware of mortality and finitude, the shadow of death lurks around the edges of consciousness. It has long been recognized that illness, and certainly hospitalization, raises these fundamental concerns. Patients frequently voice such questions as: Who am I? What is my purpose in life? What is the meaning of my illness? Why is God punishing me? In the process of coping with crisis, people often share with the pastor or chaplain concrete expressions of stressful personal and family relationships, guilt, loneliness, pain, anxiety, and fear of death and dismemberment. In this context, patients express concerns regarding ultimate values, a sense of belonging or not belonging to a community, and the ways in which they relate to what they perceive to be ultimate commitments.

In the face of such issues, the pastor or chaplain must choose whether to be open to the patient's pain. It may be tempting to remain aloof, since to be present is to become

vulnerable. James Wharton³ puts this in dramatic terms in his essay "Theology and Ministry in the Hebrew Scriptures." Using the analogy of God's ministry to and for Israel, he states that God seeks, in ministry to Israel, Israel's capacity to "minister" as God ministers. That is, "the style of God's self-giving in relationship to Israel, as minister, is the style of well-being God wants for Israel." For Wharton, the "pastoral relationship" that exists between God and Israel becomes the prototype for our pastoral relationship with others. He refers to Albert Outler's use of the image of God as therapist to warn the pastoral counselor that the Lord is free *from* us in such a way "that there is never a question of God having to use our relationship for some unknown internal gratification. Coercion, seduction, blackmail, or 'payment' are ruled out of the Lord's therapeutic style."⁴

Clearly, such measures also are ruled out of pastoral ministry. Just as the Lord manifests tender, loving care toward Israel yet maintains the "necessary objectivity and therapeutic distance" which safeguards the integrity of the caring relationship, so also must the pastor or counselor. Such ministry is "freely chosen vulnerability of relationship on the one hand and unflagging commitment to the freedom and wholeness of the beloved on the other."⁵ To a person struggling with the fear of infection and illness, such commitment is of cardinal importance. The presence of the chaplain or pastor offers the person a symbol of stability in the face of uncertainty.

Fear of Uncertainty

Much research has focused on the human body's attempt to return to its previous status when normal forms and functions are disturbed. The term "homeostasis" is applied to the state of equilibrium to which the organism seeks to return. For example, a person may experience a rapid rise in blood pressure following an acute physical or emotional shock. A variety of feedback mechanisms ensure a dampening effect on response amplitude that results in a reduction of blood pressure. Similarly, unexpected loss or change, on the one hand, or heightened creativity and

growth, on the other, usually involves some degree of risk and uncertainty and, hence, anxiety. The individual usually seeks some relief from the threat or heightened level of activity while adjusting to the new situation. In the case of grief, for example, the process of denial serves to dampen awareness of the shock of loss, providing the grieving person a longer period by which to buffer the pain.

The onset of a health crisis through disease or physical disability is accompanied by a heightened threat to stability and normal functioning. The individual longs for the moment to pass so that, with the threat removed, he or she can return to normal activities. The deeper the crisis, the stronger will be the desire to find resolution to the disorganization that has resulted. Regardless of the specifics, the crisis results in emotional stress associated with significant changes in outlook in a short time period. In turn, this may involve adaptive changes in personality of a brief or long-term nature. While crises may result in progressive movement—they may become occasions for growth—responses are often regressive in nature. Gordon Allport noted that, by definition, a person in crisis cannot stand still. "That is to say, he cannot redact his present traumatic experience into familiar and routine categories or employ simple habitual modes of adjustment."⁶ The fear of uncertainty creates a crisis of indecision that must be resolved if the person is to retrieve at least some minimal level of self-control and the ability to make basic decisions. The process may be a painful one.

One of the normal responses of people confronted by the crisis of uncertainty is a degree of regression that is marked by dependency. The chaplain must be aware of the temptation to "use" the other's need for help and support. Wharton puts this warning simply:

In ministry we may not count ourselves attached to the other in the sense that without the other our own basic needs cannot be met. If we are so attached to the other, then the other becomes for us an "it," and "ministry" becomes simply another form of self-gratification or self-aggrandizement. It is a strange postulate of faith that we do not need the other in order to minister to him or to her.⁷

Other patients, in the face of threatening uncertainty, may manifest that fear by behavior that evokes the counselor's impatience. Alan Keith-Lucas⁸ addresses this issue in elaborating on his understanding of the term "empathy." He urges that to learn empathy, one has to be free from the kind of blocks that are thrown in one's path by liking and disliking people, lining oneself up either for them or against them, instead of just caring for them whether we like or dislike them.

Fear of Stigmatization and Ostracism

To the extent that ill health carries with it a sense of isolation from the surrounding healthy society, it is often perceived as a stigmatized state by the patient. In particular, certain illnesses—for example, venereal diseases—evoke a moralistic judgment of blame, and the ill person may be held responsible for the illness. Eliot Freidson⁹ suggests that such medical problems may be stigmatized to the extent that, by social taxonomy, the illness becomes a "crime" in the eyes of the community. Of no disease has this been more true than AIDS, as indicated by community responses. For over twelve months, the case of Ryan White,¹⁰ a middle-school student in Kokomo, Indiana, was before the public. White had been refused admission to school when he contracted AIDS as a result of his treatment for hemophilia. When the school administration was ordered in court to readmit White, parents of other children angrily kept their children from classes.

In a small community in New South Wales, Australia, a three-year-old child was infected by the AIDS virus through blood transfusions in connection with her premature birth. Her pediatrician indicated that the little girl would need a lot of understanding. "The reaction among some is a message that says 'Don't exist.' If she starts picking up these messages, she could have a lot more problems in later life."¹¹ The *New Zealand Herald*, reporting the family's arrival in that country, to which they fled from Australia, noted that Eve's welcome was "a far cry from the persecution she suffered in the New South Wales town of

Kincomber, where she was shunned by the local community and banned from attending playschool."¹²

Stigma has been defined by Erving Goffman¹³ as a societal reaction that "spoils" normal identity. He suggests that the peculiar element in the assignment of stigma is the fact that while stigmatized persons need not be held responsible for the behavior imputed to them, they are nevertheless denied the ordinary privileges of social life. This is uniquely the case with respect to people with AIDS, a response that has particularly tragic consequences for the so-called "innocent victims" of the disease, such as children who have contracted AIDS from blood transfusions or infection during birth, people infected through the medical use of blood products or spouses as a result of sexual intercourse. It goes without saying that when stigma is attached to a particular act—for example, AIDS acquired through homosexual intercourse or use of a contaminated IV needle—illness may be imputed as a direct consequence of deviant, even criminal, behavior. The "guilty party" is held to be responsible for these consequences. The culture may punish, or seek to punish, him or her by termination of employment, by the attempt to force the use of "health cards" on employees in the public domain (e.g., food handlers), by denial of health insurance, or simply by ostracism.

Overt persecution and ostracism of AIDS patients owing to the hysterical response of communities is subsiding, as people's fears are answered by scientists and physicians. But their place is being taken by subtler and less publicized isolation. Industrial companies may retain employees on their payrolls but refuse them admission to their places of employment. Still more insidious is the social ostracism that reminds the person with AIDS that he or she is *persona non grata*. Thus, for example, Ryan White may have been readmitted to school, but he must use a segregated bathroom, use disposable eating utensils in the dining hall, and sit apart from other students in the schoolroom.

It is perhaps the fear of rejection accompanying stigmatization that causes such patients the greatest pain. Andrew Slaby and Arvin Glicksman¹⁴ noted that the fear of isolation is increased by the fear of rejection which they

observed in cancer patients. "Cancer bears a greater stigma than any other illness. In the mass media, cancer patients are frequently referred to as 'victims.' " The authors illustrate their point with reference to nineteenth- and twentieth-century writers, including Tolstoy, D. H. Lawrence, and Erich Segal. Hansen's disease (leprosy) continues to be associated in the minds of people with images of ostracism and rejection, due in large measure to the misperception of the biblical disease of the same name. In earlier years, tuberculosis patients suffered a similar rejection.

Slaby and Glicksman, writing in 1985 as the consequences of AIDS were only just becoming known, could hardly have imagined that within twelve months AIDS would supplant cancer as the most feared and stigmatized affliction in human history. The fears identified herein are present in AIDS patients, but with even deeper and more intense foreboding than with any other disease. In only one sense, for example, is there any less uncertainty for AIDS patients: once diagnosed, AIDS is invariably fatal. The degree of ostracism and rejection experienced by people with AIDS has been one of extraordinary intensity, so much so that even members of health care teams caring for AIDS patients have been ostracized by other members of their professions.

The degree of isolation engendered by AIDS greatly intensifies the fears that often accompany diagnosis. There are three major reasons for this.

First, the public response to the disease and to patients remains one of hysteria. A 1986 *New York Times/CBS News* poll indicated that 41 percent of the respondents thought it is possible to catch the disease by drinking from a glass used by a patient, 32 percent thought the syndrome could be spread through kissing, and 28 percent thought it is possible to become infected from a toilet seat. This response stems to a considerable extent from the proper caution exercised by the scientists responsible for the initial research into the nature of AIDS. Almost every statement was accompanied by the qualification "As far as we know." Since 1981, researchers have learned an extraordinary amount about AIDS, information that is adequate to answer

many of the initial and subsequent questions. But despite strenuous efforts to correct misinformation aimed at lessening the hysteria, many of the early myths have endured, and the hysteria remains.

Second, stigmatization of people with AIDS is a response to public attitudes of disapproval and hostility toward the two largest populations, gay men and IV drug abusers. In the Houston area, for example, public awareness of the scope of the tragedy heightened during a municipal election. The existence of an AIDS population constituted almost exclusively of gay men led to a politicization of the issue that attracted national attention. Charles Stanley, then president of the Southern Baptist Convention and a founder of the Moral Majority, stated, "God has created the AIDS epidemic to indicate his displeasure over America's acceptance of the homosexual lifestyle."¹⁵ With respect to IV drug abusers, the practice not only evokes social censure but entails the threat of felony charges.

Third, the sense of alienation is likely to be most intense with respect to family relationships. Independent of the mode of infection, relationships with spouse and family members are likely to be marked by high levels of anxiety and stress. The experience of betrayal, guilt, and the possibility that the partner may have been infected can only deepen the fear and pain. A wife may discover for the first time that her husband is bisexual or that he has had intercourse with prostitutes or other women. Children's images of their father may be destroyed and trust extinguished. Parents may also discover their sons are gay as they learn they have developed AIDS.

The hospital chaplain has a particular opportunity—and obligation—to address these issues, assuring persons with AIDS that they are worthy of compassion and acceptance. The ministry at such points is two-directional. First, it is directed to people with AIDS and their immediate circle of family and friends, and second, as a prophetic witness to the community that a humane response is the only ethically licit attitude toward these people. From a Jewish perspective, the commandment—*mitzvah*—for *bikkur holim* refers to all care and visiting of the sick. The Torah reminds us

persistently that each person is created in the image of God. One of its strongest precepts, binding upon all in the Judeo-Christian tradition, is the command to ease the suffering of the sick, a ministry that is required as long as life is present. The Talmud says that one who is in the presence of a sick person is confronting the *shechina*, the indwelling spirit of God. That is, respect for the sick is linked to respect for God's presence with that person. Likewise, failure to respect the dignity of the sick is an affront to God.

From a Christian perspective, a redemptive response to people with AIDS is required by the example of Jesus, who sought out those who were cast out of society, the defiled and stigmatized sick in particular, and promised them that they were included in the company of God's beloved. The question that AIDS presents to the church is one of identity. The church is called to be a redemptive, loving people serving their Lord, who was himself a servant. For people who claim Jesus as Lord to neglect the opportunities for ministry generated by AIDS constitutes a failure of discipleship. Neither the individual Christian nor the church as the community of the people of God has any option. The "outcasts," those with AIDS and those related to them, must be received with the same unmeasured love that Jesus embodied.

Fear of Sexuality

Although the virus may be spread by a number of methods, sexual transmission remains the primary threat to the greatest number of people. The virus is believed to have entered the United States via gay communities on the East and West coasts. It spread quickly through the gay community throughout the United States but is now well established in prostitutes; in New York, for example, it is believed that as many as 6,000 prostitutes are infected. Unless there are substantial changes in sexual behavior both in the gay community and in heterosexual lifestyles, the AIDS virus may become as prevalent as herpesvirus.

Because AIDS remains primarily a sexually transmitted disease, and because of widespread sexual taboos relating

to gay lifestyles and to prostitution, the disease evokes deep-seated fears of sexuality. Despite medical, anthropological, and religious advances in understanding sexuality, it remains cloaked in mystery. Most people hold that sexual contact should conform to societal notions of right and wrong, normal and abnormal, natural and unnatural—as judged from the point of view of the particular observer, of course. Family and societal discussion of these issues is often inhibited. The consequences of breaching these sexual mores often include condemnation and far-reaching disruptions of personal life, family relationships, and professional development and advancement. As a result, sexual practices are usually shaped by a double standard. As a simple example, parents may rigidly enforce on their children a family ethic, restricting sexual activity according to their perception of generally accepted societal restraints, but may practice quite different behavior in their own lives. The association of AIDS with high levels of anxiety focused around sexual identity was a potent issue in the 1985 mayoral elections in Houston. More recently, the staff of a Houston congregation in an affluent neighborhood proposed to present a pioneering curriculum in education directed to individual and family sexual awareness and practices, as one aspect of the parish's education of its members with respect to AIDS. The proposal was resisted strongly by parish members. The purpose here is not so much to analyze these matters as to emphasize that attempts to educate the general public concerning AIDS take place in the context of a fear of sexuality that is often deep-seated, and which the majority of people do not wish to explore.

John Boswell's study of societal, and particularly Christian, attitudes to homosexuality during the Middle Ages¹⁶ notes that many people appear to be intolerant of homosexuality because the preferences of gay people are perceived to be "unnatural." He argues that, even at the level of personal morality, the persistence of the concept of "unnatural," when it has been abandoned in nearly all other contexts, is a significant index of the prejudice that inspires it. To Boswell,

The objection that homosexuality is “unnatural” appears, in short, to be neither scientifically nor morally cognizant and probably represents nothing more than a derogatory epithet of unusual emotional impact due to a confluence of historically sanctioned prejudices and ill-informed ideas about “nature.”¹⁷

The “unusual emotional impact” of almost any societal discussion of sexual practices and taboos affects attitudes toward people with AIDS. No educational program that ignores these issues can be fully effective in informing the public about AIDS. The chaplain or counselor’s readiness to initiate such public discussion, to be open to the unspoken fears and inhibitions of people, and to encourage this openness in others will be sorely needed as the AIDS epidemic extends.

Fear of Death

The fear of death is an extension of the fear of infection and impairment. Klaus Seybold and Ulrich Mueller¹⁸ analyze this fear by reference to the Old Testament view that there is no neutral zone, only life or death, good or evil:

Earthly life is taken so seriously that when it involves sickness it can no longer be called life in the full sense of the word. Thus the omission of healing, the act that restores life, would bring the sick person nearer to death because it would leave him in the power of the realm of death. . . . *Sickness is proximity to death* [our emphasis].

In this view, a sick person has “fallen into death’s realm of power not only because sickness possibly brings death—that would be modern rational thinking—but because, on the basis of mythical thought, sickness *eo ipso* belongs to death’s domain.”¹⁹ Sickness, as the threat of death, belongs to the “dark” side of human existence. For patients or families whose lives have been devastated by AIDS or who are *afraid* that their lives may be so devastated (the “worried well”), to live with AIDS is to live in the valley of the shadow of death.

It is a common experience for staff members who minister to patients facing life-threatening illness to hear such

comments as "It is not death I fear—but dying." The anticipation of dying carries with it the same emotional pressures as the reality itself. The patient who fears he or she is dying experiences identical concerns, with the added fear of uncertainty raising the level of stress. The problem faced by AIDS patients, their family members, and those who support them is that the diagnosis thrusts each into a confrontation with death from which there is no relief. While oncologists are struggling to make the public aware that cancer is no longer an inescapable death sentence, there is at present no cure for AIDS. Most AIDS patients have already watched one or more friends die—and the deaths are not pleasant.

3

Grief Recognition and Response

The term “grief” has customarily been applied to the phenomena associated with the death of a loved family member or close friend. It accompanies the experience of bereavement, but the terms are not synonymous; the experience of grief encompasses, but is not limited to, bereavement. It is present in any situation of substantive loss or change. Thus, it may accompany such life changes as divorce, failure to achieve promotion, and other significant losses and disappointments.

Research into the phenomena of grief goes back to Erich Lindemann,¹ who investigated bereavement reactions of family members of those who died in the Coconut Grove night club fire in Boston in 1941. In a series of medical journal articles, he provided the first insights into the nature of grief. Other pioneers include Colin M. Parkes² and Peter Marris,³ two British researchers. But it is Elisabeth Kübler-Ross⁴ who is popularly associated with the effort to understand “the grief process.” Her work deservedly is recognized as ground-breaking. Others have extended her basic concepts. For example, Robert White and Leroy Gathman⁵ present three “stages” as a basis for analyzing “ordinary grief.”

Kübler-Ross’s presentation of the process, encompassing denial, anger, bargaining, depression, and acceptance, remains a useful guide, and professionals and lay people alike often recognize these phenomena in bereaved people. Despite efforts to correct misunderstandings, however, this type of presentation often appears arbitrary and mechanical, as if people’s reactions to bereavement may be

programmed or even manipulated. If the terms are written on a chalkboard in sequence, it does appear that each "stage" is a prerequisite for the next. A more fluid or flowing format is needed to represent the process of normal grief. Figure 2 is one effort to emphasize this aspect.

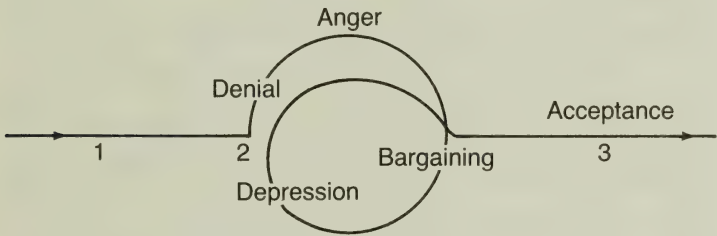


Figure 2

One's life may be moving along in a more or less stable manner (1), when the death of a loved family member or friend interrupts that course (2). In a sense, the direction of one's life changes abruptly, regardless of whether the death was sudden or anticipated, as one attempts to come to terms with the loss. Using the Kübler-Ross material as a guide, we may say that the bereaved person may experience such responses as denial, anger, or depression, as he or she strives to accept the loss and resume the day-to-day responsibilities of life (3).⁶

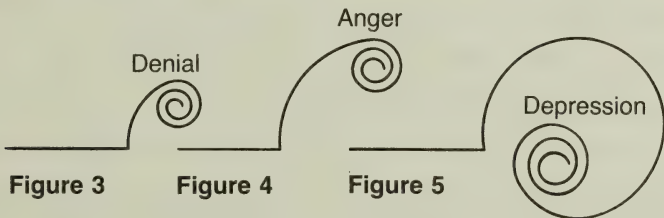


Figure 3

Figure 4

Figure 5

The diagram has an additional advantage. It is well known that the task of integrating the experience of bereavement into one's ongoing life is very much an individual matter and that the process may be blocked from reaching resolution. Thus, for example, a person in grief

may never move beyond a profound level of denial, refusing to come to terms with the tragedy in his or her life occasioned by the death (Fig. 3). Such a response may verge on the bizarre. For example, a couple whose teenage son was killed in a motorcycle accident insisted on keeping his bedroom precisely as it was when he left the house—even to the half-consumed bottle of soda on his bedside table. It was as if they intended him to be able to walk back into an undisturbed room when he returned from his interrupted visit to a friend's home. Alternatively, a grieving person may experience deep anger at the death of a loved one and never find the freedom to lay that anger aside (Fig. 4). Again, it is a common experience for a person in grief to slip into a level of depression that may become pathological, requiring extensive psychotherapeutic intervention (Fig. 5).

Marris proposed that grief is a generic term which encompasses not only response to bereavement but may characterize *any* substantive loss or change. Research since the early seventies has substantiated this concept. Thus, divorce, unemployment, the birth of a disabled child, failure to achieve a desired promotion, damage to or loss of a prized object, amputation (for example, mastectomy, hysterectomy, or the loss of a limb by an accident victim or diabetic patient), the empty-nest syndrome, and countless other occasions of loss or change may result in an intense grief experience.

It is now clear, further, that *anticipated* grief associated with feared loss or change may have precisely the same effect. In some senses, the fear of loss or change may occasion more intense feelings of grief than the actual event. Bowlby⁷ recognized this factor. Noting its importance to understanding human behavior, he developed models that derived from his work with children and applied them to adult grief. Parkes contends that anticipated and unanticipated losses have different emotional implications. He is not prepared to say whether one kind of loss is more painful than the other, but he finds that the trauma of unanticipated loss is the more disabling.

Awareness of the complex network of human perceptions and experiences that determines the course of grief

indicates that response to the grieving person is likely to be equally complex and intense. The helping person must be ready to enter the other person's world of pain—to the extent that it is ever possible to enter another's world. This is particularly the case with respect to ministry to people with AIDS. First, as with any terminal illness, these patients are caught up in dealing with their own deaths. But the ability to accomplish that is affected by other factors with which AIDS patients must deal *at the same time* as they struggle with the fact that they are terminally ill.

Anyone tested and found to be antibody-positive to HIV must come to terms with multiple threats evoked by a series of potential or real catastrophic losses, such as the following:

- If married, relationships with spouse and family members
- The sense of well-being and security as a healthy individual

- The level of self-image and self-esteem that has been reached before knowing the result of the test or becoming ill

- Identity as an active, productive member of the community

- The respect of peers

- The sense of acceptance as a worthwhile and acceptable person

- Independence

- Dreams, aspirations, goals around which life has been organized

- If a parent, watching the family grow up and mature

- Other particular personal losses

With the acute stage of the disease, patients suffer increasingly severe physical, emotional, and mental losses, such as the following:

- Loss of the ability to continue normal activities, including food preparation, basic personal hygiene, shopping for supplies, and even the ability to feed oneself

- Acute health losses, such as vision, control of bowel and bladder, mental acuity, and massive deterioration of all physical and rational functions

- Loss of life itself

4

Pastoral Care of People with AIDS

The mode of pastoral response is illustrated by the traditional pastoral responses to people in grief. Experience suggests that the most basic need is a climate in which the grieving person feels free to tell the story of his or her grief. This in turn must be shaped by an openness to the patient's needs, which, in the case of AIDS, are likely to be comparable to those of people facing other catastrophic diseases, though they may be experienced more intensely. The following aspects of pastoral care to patients should be addressed by the counselor or pastor:

1. Because the AIDS patient usually has experienced rejection and derogation, he or she is searching for acceptance and understanding. In particular, gay men seek understanding and acceptance of their being and lifestyle.
2. The degree of hostility to gay patients indicates a strong need for advocacy of both their personal needs and their patient rights.
3. In end-stage disease, advocacy may include representing the patient's wish to discontinue invasive therapies and to maintain comfort without life-prolonging intervention.
4. Since many patients with AIDS face loss of mental faculties, the caring person may raise with the patient the matter of arranging for a power of attorney should mental deterioration make it impossible for the patient to act on his or her own behalf.

5. In that case, the pastor or chaplain should initiate discussion of the need to take care of personal business, including the need to prepare a will. It has been our experience that many patients initiate these discussions themselves, while others do not.
6. People facing the threat of imminent death are already looking for some way of finding meaning, both in their life to that point and in their approaching death. The caring person should be alert to the need to explore these very personal issues.

James Wharton has pointed out that in the setting of catastrophic illness or trauma, it is inappropriate to "preach at" the patient.¹ The appropriate attitude of ministry is one of care and compassion that is addressed to the stated needs of the patient or family member. It is manifestly not the time or place to engage in "missionary" activity designed to proselytize, or to take advantage of the crisis situation to achieve some end chosen by the counselor. Ministry should be responsive to the person in crisis and will usually be a listening ministry for which the patient or family member sets the agenda.

One of the most creative attempts to analyze this listening role is suggested by Alan Keith-Lucas, whose material is a useful addition to Wharton's more theologically based contribution. Keith-Lucas² suggests that effective help and support are offered only when composed of three elements: reality, empathy, and support. He presents this format in summary via three caring responses:

REALITY: This is it.

EMPATHY: I know that it must hurt.

SUPPORT: I am here to help you if you want me and can use me. (*Or, more succinctly*) You don't have to face this alone.

Reality

The acknowledgment of the situation—the reality—that the patient is facing is fundamental. Reality means not discounting the other person's dilemmas and problems or

offering false reassurance: to protect someone from the truth is to make a very serious judgment about that person. Keith-Lucas refers to a social work term to amplify his meaning. He describes the introduction of "pieces of reality" deliberately introduced into a caring situation as the identification of "pieces of difference." These include delineating the areas of common ground and purpose shared by both parties, expressed in the patient's terms, and based on the counselor's openness to the impact this process is making on the other. Most important, such confrontation with reality may only be undertaken if the pastor or chaplain is prepared to stay in the situation and with the shock. Reality by itself is harsh and can be destructive. It is only reality approached with empathy and support that is a truly caring ministry. Reality means not being indirect, and it must be presented without attempts at justification. It must be remembered, also, that the helping person is in a position of power—he or she is well, the patient is ill—and the question of implicitly assuming the latter's dependence must be faced explicitly. Consequently, the assessment by the caring person of the capabilities of the patient—what he or she is able "to bear"—ought not to be a hidden agenda.

Empathy

Keith-Lucas defines empathy as the ability to know, or to imagine, what another person is feeling and, as it were, feel with him or her without becoming caught in that feeling and thereby losing perspective. He stresses that empathy does not involve "softening" reality. It is the carer's response to what the patient is experiencing. Thus, empathy is not merely sympathy or pity. Sympathy, especially, has received a bad press; there is a place for expressing sympathy to another in pain. But without the deeper sense of "feeling for" the other person, it may be a formal, even cold, message. In its place, Keith-Lucas offers his own description of empathy—"the act of loving imagination." The caring person can never say, "I know just how you feel" but must be ready to communicate that he or she

knows it must hurt. It is of cardinal importance to recognize that this caring response is given out of such love that it is not restricted by one's liking, or even by one's dislike, for the other.

Even when the situation has been assessed and faced openly, recognizing the realities of the situation and what has been accomplished empathically, help or care is incomplete. It is possible to share with an AIDS patient, "This is a painful time for you," and identify the reality caringly, but still leave the patient feeling desperately alone and forsaken. One of the strongest needs of the AIDS patient is to know that another not only cares, but cares enough to stay in the situation with the patient. This is the third element in the caring relationship.

Support

Support in turn may be offered at a number of different levels: physical or material, emotional or psychological, and what can be most simply identified as "spiritual" or "religious" support.

Material support may include such practical issues as putting patients in touch with attorneys and acting as the patient's advocate with medical or nursing staff or in relation to the patient's family, such as mediating reconciliation if both parties are open to that possibility. Support may take the form of offering counseling services, remembering that if the patient is married and has children, the needs of the younger family members also need to be acknowledged.

The AIDS patient's experience of isolation and, often, ostracism may leave him or her vulnerable to feelings of being deserted and devastatingly alone. While many families have made great sacrifices of family security to enable them to provide constant and strong support to patients, there are other situations in which the patient has been abandoned by family and friends and literally left to die alone. The need for acceptance, respect for the personhood needs of the patient, and for a place to die indicates that *emotional support* embodied by the presence of those who

care is critical. One imagines, for example, what must have been the impact on the leprosy patients on the island of Molokai when Father Damien joined them. Support includes "being there," but it does not mean mere presence. It may include offers of direct help, touching, feeding, and standing with the patient when others are unable or refuse to do so. It is not merely to say "I am here to help you" but to make the offer, "I am here if you want me and can use me."

The caring person's *spiritual or religious ministry* emerges from the pastor's identity. When a pastor or chaplain enters a room or engages in a conversation, religious and theological meanings are implicitly or explicitly present. From time to time, the religious identity may be a barrier to ministry. It is up to the counselor to address such issues. The pastor or chaplain also has the opportunity to be present as a caring person who manifests in that presence an accepting, loving ministry which may well contrast with uncaring and hostile expressions. It has been our experience that people with AIDS often bring a stereotypical expectation of rejection of themselves by the religious community. Pastors and chaplains should remember that they are not responsible for the impressions of ill will created by the reactions of other people. They are only responsible for the degree of compassion with which their own ministry is offered. If offered with sensitivity and love, ministry speaks for itself and invites the trust of the patient in what is potentially a deep relationship that is reconciling and redemptive. It goes without saying that this ministry is one that excludes a kind of empty moralizing which treats the other person as an "it" (see note 1).

The deeply held convictions of some pastors may make it difficult, even impossible, for them to provide effective pastoral care to AIDS patients. They may find it difficult to put aside moral judgments toward people with AIDS and permit such judgments to stand in the way of ministry. This is not to suggest that clergy should lightly ignore their own value systems, but to make the point that not all clergy will wish to engage in ministry to people with AIDS or be suited to this ministry.

Pastoral Care of Families

Patients cannot be viewed in isolation from their circle of family members and friends and, in the case of gay men, their lovers. Much of what has been offered with respect to patients applies also to the circle of people around them. Their grief is the grief of loved ones threatened by the loss through death of a son, brother, daughter, or sister. But, as for the patient, so family and friends struggle to come to terms with the disease and its inevitable end, in the context of society's attitude toward AIDS and people with AIDS. There are two principal means by which the disease is contracted: through sexual intercourse or by infection from use of shared IV drug paraphernalia. Apart from infection due to blood transfusion or the use of blood products in such instances as care for hemophiliacs, the contracting of AIDS is associated with lifestyles that are rejected widely by society, often with hostility. Thus, parents may learn at the same time that their son is gay and that he has AIDS or an AIDS-related condition. Parents may learn that their son-in-law is bisexual or has slept with a prostitute and that their daughter has been infected by him. Other family members may learn that the infection can be traced to hospital procedures—transfusion or use of contaminated blood products. In all these instances, the grief of families and friends is just as stark and painful as that of the patients.

In many cases, denial and confusion will often be replaced quickly by a sense of helpless rage. Such anger may be vented toward the "guilty" one—the doctor or hospital, the infecting husband or lover, the son or daughter whose drug use left him or her susceptible to such a threat. Pastoral care in such circumstances will be shaped by the specific circumstances in which the pastoral support is offered. Once again, listening to the "story," the account of the tragedy in the lives of the affected people, is likely to be the most effective starting point. But, as pastoral care staff members whose background is primarily in a "Rogerian"-based³ perception of their roles well know, listening, however caring and effective, does not meet every aspect of human need. For example, individuals may be so overcome

by the degree of their suffering that they are unable to act, or to act within reasonable limits of behavior. When a person is afflicted by seemingly unbearable pain and is unable to function it may fall to the helper to assist the grieving person to reestablish some limited degree of control by recourse to the authority of the clergy's professional office and function.

Pastoral Care to the Community

The AIDS patient must be recognized as an individual whose integrity must be respected, and who has a claim on the pastor for acceptance as a person. Such acceptance does not imply either acceptance or rejection of the patient's lifestyle, only that each person is a child of God. But neither the pastor nor the patient (and family) functions in a vacuum. Each is a member of a wider community. Christians bear a unique and challenging responsibility to minister not only to the people immediately affected but to the societal groupings of which they are a part. This may mean interceding, at the patient's request, with an employer or assisting the patient to obtain legal assistance in connection with such matters as continuing health insurance and other benefits. Campus chaplains, military chaplains, clergy serving as denominational administrators, and others are responsible to the structures of discipline in their organizations and participate in practices that determine courses of action: for example, in the decision to test all military personnel for the presence of AIDS antibodies. The counselor must be "present" to others who will be involved in a particular situation. These include supervisors who are sensitive to the issues of confidentiality and privacy, those who are directly related to the employee through the chain of command, and others who, while not involved directly with a specific case, are sensitive to the manner in which the decision to test was made and its impact upon the careers and welfare of both themselves and others. (This issue raises a further matter: namely, the prophetic aspect of pastoral care, addressed by us in an earlier volume.⁴)

Two other functions of ministry involve practical responses by clergy. First, clergy have an opportunity to

assist in educating their particular communities with respect to the impact of AIDS on individuals and societal groups. In light of both the prevailing hysteria which characterizes the responses of many people and groups to the disease and the profound ignorance of the disease itself, the need for public education is urgent. The need is partly for accurate medical information, but it is also essential that public discussion occur in a reasoned and less emotional manner than is currently the case. Clergy have the opportunity to address the unfounded fears of the well community, to ensure that public statements are informed by accurate medical information, and to assert the need for compassion toward the afflicted, both patients and family members.

Second, the church's role as a mediating and reconciling agency in the community suggests that that role should inform those of us who have become alert to the call to ministry in the AIDS crisis. The mushrooming effects of the disease and the emotions of hurt and bewilderment it has stirred will be alleviated only through the efforts of people who meet the challenge with compassion and, to the extent possible, the proper level of dispassionate response, one that encourages people to work and talk with one another to heal wounds created by fear and grief.

Pastoral Care to the Caregivers

The medical, nursing, social work, and other professionals who care for people with AIDS or ARC work in a setting in which chronic grief affects every aspect of care. As the numbers of AIDS patients exploded in the early 1980s, staff members prepared to work with these patients were met by outright censure by other institutional staff members. This peer rejection is fading, but to it is added another factor—chronic grief. In light of the initial peer pressures and the extent of grief attached to caring for dying patients, there has been a “self-selection” process. Staff members who work with people with AIDS are there because they care, are sensitive to the needs of patients, and find personal satisfaction in the relief of suffering. But such medical and nursing care is draining, and the pastor or chaplain should be alert to opportunities to listen, not

only to the stories of patients and family members but to those of staff members also. Such avenues as formal staff report sessions in which members are able to vent anger and despair—the normal group support sessions—might be augmented by informal social gatherings in which staff members meet socially in settings in which AIDS/ARC issues are not broached.

The Pastor's Own Needs

Grief ministry presents a challenge to the pastoral caregiver that differs from other types and levels of involvement. Clergy who counsel are aware that it is to their own benefit, professional growth, and integrity as counselors to obtain supervision of their work. A consultant's oversight enables the counselor to deal with the burden of questions about one's continuing competence and leads to openness to areas of needed professional and personal growth. This process also assists the counselor to protect the client's interests.

In the area of grief ministry, and particularly with respect to a population of terminally ill patients, pastors and chaplains must be alert to their own personal needs. The loss or threatened loss of a loved family member or friend is an intensely painful experience for the survivors. It is also painful to witness. The counselor is powerless to reverse the dying process. Maintaining a sensitive, supportive ministry to a dying person offers clergy an avenue for investing the emotional energy evoked by the situation and may alleviate the sense of powerlessness. But just as the dying person and family may experience anger and frustration, these feelings are also likely to compound the offering of ministry.

If lay ministers are drawn into this ministry, participating with clergy in grief support, it will be incumbent upon clergy sponsors to afford opportunities to lay group members to "debrief" following their periods of intensive involvement. The care of lay participants in a grief support program is similar in importance to the ministry itself.

One of the most important factors is that those who minister must acknowledge their own mortality. Indeed,

those who care for dying people must address in their own lives the critical issues that terminally ill patients face. For example, the final completion of personal business, such as making a will, is just as important for the counselor as it is for the patient. Being involved in such a ministry becomes an educational process. Thus, programs to care for people with AIDS should be structured to offer training, supervision, support, and the opportunity to explore the ways pastors, chaplains, and lay persons can cope with anxiety, stress, threats to relationships, and losses.

5

Ethical Issues

Moral questions regarding the care and medical management of people with AIDS do not differ greatly from those frequently addressed in relation to other terminal diagnoses. Four features of AIDS, however, cast in a special light familiar concerns of confidentiality and privacy, quality of life and care, treatment decisions, and duties to the sick. These four distinguishing features are: (1) AIDS is an infectious, presently fatal disease, (2) social reaction to people with AIDS differs from reactions to people with other terminal diagnoses, (3) the comparatively rapid, progressive, and destructive impact of the disease quickly erodes a patient's quality of life, and (4) effective ministry to people touched by AIDS seems to require certain character traits or virtues that appear less crucial when ministering to other people.

The discussion of moral issues provided here is restricted to matters most likely to come to the attention of a counselor ministering to a person with AIDS or to his or her loved ones. The purpose of this discussion is to identify a series of issues and concerns, rather than to provide specific answers to complex questions. The task of discerning right and wrong or good and evil in a moral pluralism is more difficult than in contexts where everyone embraces a single moral vision.¹ Recognizing that people touched by AIDS are a diverse group, not necessarily sharing values with or ranking values in the same order as the one who ministers, is a necessary first step toward providing a ministry that respects persons and their individual moral choices.² Rather

than viewing the flourishing of a variety of moral positions as an indication that somehow moral agents and society have lost their way, perhaps we should celebrate this variety as a safeguard against self-righteousness and intolerance. The better course in such an environment seems to be a dialogue directed toward greater mutual understanding between people who embrace differing moral visions. By becoming clearer about the concepts, principles, and values that divide people, perhaps an atmosphere will be engendered in which there can be mutual respect based on a greater understanding of reasonable differences, even though agreement may never be reached about some important issues.

Privacy and Public Health

It is a well-established principle in American law that persons have a right to privacy.³ This legal principle corresponds to the moral principle of autonomy or respect for persons. The moral principle, like its legal parallel, is the basis for an individual's right to be self-determining. In situations where an individual is infected with HIV or is diagnosed with ARC or AIDS, the ability to be self-determining and to pursue life plans may depend upon this information's being kept secret.⁴ In short, information concerning a patient's status should be kept confidential, all things being equal, in order to protect and promote that individual's right to be self-determining.⁵

Relationships with family, friends, and co-workers might be in jeopardy if the patient's secret is disclosed without his or her consent. Many patients attempt to restrict the truth about their physical condition to individuals who have a need to know. Their fears of disrupted relationships, lost employment, canceled insurance, or loss of housing, based upon their knowledge of reactions to people suspected of having AIDS or actually diagnosed with the disease, are often well grounded. The potential or actual loss of these opportunities can have a negative effect upon a person's self-esteem, self-actualization, quality of life, and immunological function.⁶

The moral principle of respect for persons requires that individuals be given the opportunity to decide what they will or will not do and what will or will not be done to them. The legal right to privacy is the basis for the doctrine of informed consent,⁷ "the willing and uncoerced acceptance of a medical intervention by a patient after adequate disclosure by the physician of the nature of the intervention, its risk and benefits, as well as of alternatives with their risk and benefits."⁸ In the context of HIV infection or AIDS-related diagnoses, rules of informed consent require minimally that individuals be informed if being tested for antibodies to the AIDS virus and that their antibody status or AIDS-related diagnosis may not be disclosed without their permission. The consent of the patient is vitally important, since his or her ability to be self-determining could be severely and adversely affected by the publication of this information.⁹

Even though self-determination is highly valued in Western morality and American law, one person's interest ought not have priority over another person's interest.¹⁰ In short, an individual's liberty to pursue his or her goals is constrained by a duty not to harm others in that pursuit. The moral principle of nonmaleficence forbids doing harm to others and the moral principle of beneficence requires that individuals promote the good of others.¹¹ In the context of AIDS, these principles require that people infected by the AIDS virus not put other people at risk of infection without their consent. In addition, these principles can be understood to justify actions that limit the liberty of infected individuals in order to protect others from infection. The balance of interests to be sought is one that protects the self-determination of infected individuals and protects the health of other people. Thus, since people infected with the AIDS virus reasonably can be presumed infectious, one's duty to keep confidences or secrets may be limited if there is an unreasonable threat to the welfare of others.¹²

This concern to protect individuals from inadvertent infection surely requires that sexual partners of people carrying the AIDS virus be informed of this fact. In addition, procedures are warranted to protect recipients of blood,

blood products, or organ implants from infection. The doctrine of informed consent, however, would require that donors of blood or organs be informed that tests will be performed to determine whether the donated products are free of the AIDS virus.

This same concern to protect people from inadvertent infection could justify educational programs directed at prospective mothers. Women who plan to become pregnant or who are pregnant should be warned about the potential threat to a fetus which might result from high-risk activities—for example, IV drug abuse or sexual intercourse with a man known to be infectious. Similarly, pregnant women who are infected by the AIDS virus may wish to consider terminating the pregnancy in order not to bear an infected infant. Abortion, as is well known, is the subject of a vigorous moral debate.¹³ However, it seems reasonable to consider probable infection by the AIDS virus and an early pediatric death as indications for abortion comparable to prenatally diagnosed fetal defects that are so considered.

Finally, a concern for public health would appear to support arguments favoring mandatory screening of prostitutes for HIV infection. However appealing and justifiable this proposal appears on the surface, implementation and enforcement of such a program seem impractical, since "only where prostitutes are licensed and subject to periodic health examinations could such screening, when used in conjunction with license revocation, interrupt the transmission of HIV without creating enormous problems."¹⁴ In addition, reasonable questions could be raised about the justice of singling out one group for screening, control, or quarantine. If sexual activity is a justification for mandatory screening, then all people who are sexually active, according to the principle of justice, should be tested. It seems unfair to target prostitutes for this type of invasion of privacy, whether they work legally or illegally. All things considered, educational programs designed to inform people about safe sex practices and other risk reduction practices appear preferable. In addition, educational programs about the transmission of the AIDS virus and the possible effects of infection and progression of the disease might embody

an additional benefit of shaping attitudes that are more understanding, compassionate, and sympathetic toward people coping with the consequences of HIV infection.

Quality of Care and Quality of Life

Even though the number of people with AIDS and related conditions continues to increase at a rapid rate, many physicians are basically ignorant about the disease. Further, the manifestations of the disease can be so extensive that no single medical specialty could be expected to provide optimal care. Medical management is complicated further when it is recognized that therapeutic agents which normally function effectively may not be as effective in this population. These difficulties in treatment and in obtaining competent medical care can have a negative impact upon a patient's quality of life.¹⁵

Not only are treatment failures potentially detrimental, but some patients have encountered clinicians who do not wish to fulfill their professional obligations to provide care. Clinicians do not need to be overt in their objections about treating people infected by the AIDS virus; subtle verbal or behavioral messages can be equally effective in communicating to patients that particular clinicians are not interested in them as persons or in providing them with medical or supportive care. Personal or professional abdication of duty to provide care can convey to patients the message that they are unworthy of care and that their lives are not worth saving. Clearly, some clinicians prefer not to treat people with AIDS and related disorders because of their unfamiliarity with the condition and their desire for patients to receive more competent and comforting care at the hands of more experienced personnel. Referral or treatment refusal for this reason is not morally culpable. On the other hand, treatment refusals based on discriminatory judgments regarding particular patients or on unfounded threats to the clinician's own welfare are morally culpable. Such refusals to care are contrary to the Hippocratic tradition of medicine in which physicians voluntarily assume certain risks in order to provide their healing services to humanity.¹⁶

Deficits in the care of people with AIDS and related conditions can complicate their physical status, lessen their sense that life is worth living, and, based upon quality-of-life considerations, lead to refusal of treatment before the time at which stopping the treatment would be indicated. Clergy should not be surprised to hear patients speak about these issues. Patients may be very angry, feeling that they are being treated unjustly, not respected as persons, and not being perceived as persons of dignity and value, worthy of compassionate, competent, and humane treatment. There may be instances in which a pastor should be an advocate for patients in order to ensure that they receive humane treatment and a fair share of available medical resources.

Treatment Decisions

As pointed out in the section on privacy and public health, it is well established in law and ethics that mature persons have a right to be self-determining. This right extends to decisions regarding what is done to one's body in clinical contexts. Like all other competent individuals, people with AIDS or AIDS-related conditions, or who are infected by the AIDS virus, are free to accept or reject proposed conventional or experimental therapies for AIDS-related infections or malignancies.¹⁷ They also are free to decide for or against participation in experimental protocols designed to correct their underlying immune impairment.¹⁸

It is not uncommon, however, for people infected by the AIDS virus to have symptoms of neurological involvement. More specifically, dementia and cognitive impairment may be present as initial symptoms of HIV infection or as symptoms that develop later during the natural history of the disease. It is possible that such neurological impairment can be so severe as to render a patient incompetent and therefore unable to make informed decisions regarding treatment.¹⁹ The laws of each state determine the "next of kin" who may assume the responsibility for the care or custody of an incompetent patient. The fact that state statutes specify blood relatives as the primary legal surrogate for an incompetent person can be an occasion

for conflict. For example, a homosexual male may have a lover who is in the same relationship as a spouse in heterosexual marriage. The preference of a gay patient that his lover be recognized as his next of kin does not have legal sanction in any jurisdiction. Unless appropriate legal documents are executed by a person before becoming incompetent, the laws regarding next of kin prevail. In this situation, it is therefore advisable for a patient to execute a durable power of attorney identifying and empowering the chosen person to act in his behalf when he is unable to do so. This process can assure that a lover is recognized to have the appropriate authority to make decisions should a person with AIDS become incompetent.²⁰

There also may be circumstances in which a person infected with HIV becomes estranged from his or her family because of behavior of which they disapprove. Whether the behavior is homosexual contact, IV drug abuse, or having intercourse with prostitutes or other women, disruptions may occur within family relationships such that a patient may not wish a family member to make decisions on his or her behalf. People who are in these circumstances may wish to identify and empower a trusted friend through a durable power of attorney or issue other advance directives, such as a living will,²¹ to instruct physicians about their care during periods of incompetency.

Clergy should be knowledgeable about the legality of these alternative methods of decision making. The arrival of family members on the scene can occasion significant conflict with the duly appointed surrogate concerning who is authorized to make decisions for an incompetent patient. Durable powers of attorney and advance directives are extensions of an individual's right to be self-determining. These legal instruments are commonly used and rarely challenged when properly executed. The surrogate presumably is knowledgeable about the values and wishes of the incompetent patient and acts in accord with the patient's prior declarations.

Treatment decisions regarding experimental medications intended to destroy the AIDS virus or restore the immune system are subject to the same general moral considerations as decisions regarding conventional therapies

for infections or malignancies. The federal government has issued stringent regulations concerning the conduct of experiments involving human subjects.²² A primary concern in the crisis of AIDS is to make promising therapeutic or palliative agents available to all people who might benefit from them while, at the same time, protecting desperate individuals from useless or dangerous treatments. In particular, chaplains in medical centers where experimental research is undertaken should be alert to the increased risk and hope that these trials represent to patients. They ought also to be sensitive to the struggle that patients experience in an effort to weigh the anticipated risk and benefit of any proposed experimental intervention. Chaplains may function as patient advocates in these circumstances with a view to protecting patients from overzealous researchers and, alternately, to ensure that patients have equal access to potentially helpful treatments.

Unfortunately, at present all "treatments" aimed at destroying HIV or at restoring the underlying immune dysfunction are experimental in nature. The complications of the untreatable AIDS virus infection may lead to death. The tragedy of this situation is often compounded by the rapid and severe debilitation that can precede death. Patients may decide that life is no longer worth living or that the quality of life no longer justifies the pain and suffering necessary to continued existence. Thus, a patient, or his or her surrogate, may decide that no further curative or palliative treatment is indicated. This decision may be difficult to make, because the course of the disease can be very erratic. Some patients are free of acute illness for long intervals of time. Others are chronically and debilitingly ill. A reasonable objective in this situation is to identify the point at which one can accept death without being deprived of "good time." Stated differently, a reasonable goal is to live as long as possible, provided that the pain and suffering associated with living is acceptable. In the final analysis, the consensus is that these decisions are properly made by a competent patient or an incompetent patient's surrogate. When decisions are made to cease attempts to prolong life, the goal of medical and nursing care changes to one of providing maximum comfort to the dying person

and his or her loved ones. The pastor or chaplain can be an important part of the process of making the decision to accept death and ensuring that the patient's death occurs in as dignified and humane a manner as possible. The counselor's role in these circumstances, as well as the role of all other individuals, is to facilitate the self-determination of the patient and the compassionate care of all concerned.

Some patients may not wish to await death as a consequence of HIV infection and its complications. Some people with AIDS have committed suicide in order to avoid the debilitation and dehumanization which they perceive to be their destiny. Obviously the morality of suicide in any circumstance, including terminal illness, is debatable. The pastor or chaplain may be consulted by patients who are contemplating this course of action. Specific guidance as to how to respond to a suicidal patient cannot be provided here, but there is a substantial body of literature that recounts religious and secular arguments regarding the morality of suicide.²³

Similarly, patients who are physically incapacitated but mentally competent may desire to commit suicide but are unable to do so without assistance. Thus they may solicit the aid of a family member or trusted friend. As with suicide, the pastor or chaplain may become aware of this intention and the proposed cooperative action. Moral philosophers and moral theologians have debated the morality of assisting suicide, and this literature may be helpful in deciding what role and responsibilities a counselor has in these circumstances.²⁴

As morally controversial as suicide and assisted suicide may be, the subject of "mercy killing" is morally even more perplexing. Some people with ARC or AIDS may become incompetent and incapacitated. This situation may prompt surrogates or caregivers to consider death as a greater good than life. Analogously, ending life may be viewed as more morally right than perpetuating the life of one who exists in such a state. As with the subjects of suicide and assisted suicide, there is a substantial debate about the morality of hastening the death of an individual in this situation, especially when the patient has made no declarations concerning his or her wishes should such a situation develop.²⁵

The act of killing an individual in this condition is illegal. However, judges and juries on occasion have interpreted these killings as acts of mercy rather than acts of malice.²⁶ Moral judgments about an act of killing in such circumstances would depend generally upon whether it is perceived to be a benevolent or malevolent action. The pastor or chaplain could be drawn into discussions with potential actors about what should be done, the morality of the proposed action, and the possible legal consequences to the actor. The frequency with which mercy killing is considered for severely demented or severely debilitated patients with HIV infection ought not to be underestimated. Clergy would be well advised to become familiar with the moral discussion of mercy killing in order to formulate their own position and to be better able to consult with people who raise this issue.

Duties to the Vulnerable

In fulfilling one's duties to minister to people touched directly or indirectly by AIDS, the pastor or chaplain caring for these people may need to embody and express certain virtues more frequently than in other situations of ministry. These virtues may be required because of the social context in which ministry occurs. People with AIDS and their loved ones frequently are stigmatized by friends and strangers. Their isolation, whether imposed by others or self-imposed, generates a special need and opportunity for a reconciling ministry.

Because of the severity of AIDS and the fearful response of many people to this disease, patients and their loved ones may feel less worthy of respect and compassion. Pastors have opportunities to affirm the dignity and worth of everyone involved by providing a compassionate ministry toward people who feel socially outcast. Compassion expresses a personal regard and often leads to acts of benevolence. Compassion, however, can also be expressed in situations where action is impossible or would not be effective. Here compassion may take the form of being present with and to people in distress and entering into their experience. By so doing, the pastor or chaplain affirms

the inherent and conferred value of these people who feel displaced to the margins of society.²⁷

Loyalty to people suffering the consequences of HIV infection is equally as important as a compassionate attitude toward them. So often people with AIDS and their loved ones experience a series of losses and disappointments. People who normally could be relied upon for support and understanding frequently abandon them. Patients may fear that physicians will lose interest in their cases, since a cure is presently beyond reach and all victories are partial and of short duration. When life becomes a series of physical, material, emotional, and social losses, the fidelity or loyalty of a chaplain can be an important resource upon which patients and their loved ones can rely. The pastor or chaplain's commitment to abide with the relevant individuals throughout the ordeal can become a source of strength and comfort. Such fidelity can be a manifestation of the fidelity of God's love toward the affected individuals.²⁸

A ministry that is compassionate and loyal may require courage.²⁹ Courage is not necessitated by the risk of infection mistakenly perceived to be present in casual contact with people with AIDS. Rather, courage may be required in order to withstand the criticism, ostracism, and discrimination expressed toward the pastor or chaplain by the broader community because of the commitment to minister to people with AIDS and their loved ones. The sort of courage to be exhibited in this context ought to be a basic characteristic of the people of God; it is obligatory, not optional. In short, the pastor or chaplain and the people of God, if they are to be faithful to their identity and mission, must be prepared to risk rejection and ridicule in order to fulfill the requirements of discipleship.

Finally, people with AIDS and their loved ones, according to the witness of scripture, are made in the image and likeness of God. This affirmation requires of God's people an attitude and conduct that respects the inherent worth and dignity of every person regardless of physical condition or status in life. The moral principle of justice requires that each person receive his or her due.³⁰ In the context of pastoral ministry, justice requires that the claims of every person for redemptive ministry cannot legitimately be

denied. In short, the marginalized and socially dismissed have equal claim upon the compassion, mercy, and love represented by and in the pastor or chaplain and God's people. Justice also requires that people not be discriminated against regarding opportunities for health care, social services, and the basic necessities of contemporary living. Abraham Heschel notes that God's righteousness, and humankind's justice derived from it, are characterized as having a bias for the "poor" or vulnerable (Isa. 30:18). Heschel observes that God's concern for justice is based in God's compassion for humanity (Ex. 22:22-23, 27). God's attribute of justice and concern for compassion are not incompatible. Heschel notes, "Cain, slaying his brother, does not receive the punishment he deserves. Though justice would require that Abel's blood be avenged, Cain is granted divine pardon and protection."³¹

The temptation is strong in the midst of the AIDS crisis to point fingers of blame at people caught in the whirlwind of this lethal epidemic. This tendency ought to be resisted, both by the people of God and by society. The witness of scripture and the history of God's people teach that in situations of pain and suffering, love and mercy should characterize the response. Compassion, loyalty, courage, and justice, therefore, are not only traits that should characterize the response to AIDS, but are virtues which define the duties that all moral agents owe to people touched directly or indirectly by this new disease.

6

Three Cases

The following cases suggest three situations in which pastors and congregations may be called upon to minister as the crises due to HIV infection grow in intensity. Pastors may use them as a means of reflecting on their own values, attitudes, and decisions and the pastoral care needs that emerge in responding both to people with AIDS and to their loved ones. They also may be used to help members of congregations discuss these issues. Alternately, clergy study groups may use the materials to focus discussion on issues arising from the AIDS crisis. Members of clergy groups may find that the effectiveness of such discussion is enhanced by securing the participation of a hospital chaplain or other health care provider who is experienced in working with people with AIDS.

CASE A

A thirty-six-year-old man, Alan Anderson, awakens with a sore throat. He mentions it to his wife and, forty-eight hours later, attends a local medical clinic. All appearances indicate a fungal infection, and he leaves the clinic with a prescription. A month later, he is experiencing minor night sweats, mild fevers, and fatigue. He makes an appointment to see his family physician, who suggests hospitalization and further tests. He procrastinates, suggesting that he has been under heavy strain lately, including the planning for his firm's sales conference in New York and, since his return, preparation of his review of the conference for presentation to the division

staff. In accounting for his overtiredness, he argues that it is nothing that three weeks' vacation cannot solve; he will soon be back on his feet. He just needs a break, and "it will go away." He has certainly earned a vacation and has been planning a trip with his wife for three months. At the end of the first week of his vacation, he is hospitalized with a high fever, loss of appetite, severe sweats, swollen lymph nodes, and shortness of breath.

CASE B

A twenty-year-old man, Bryan Bates, experiences increasing anxiety as he is bombarded by media presentations, journal articles, and discussion at the office concerning the AIDS epidemic. He tries to prepare himself for the ordeal of visiting an AIDS testing center. He is afraid to submit to the tests, although he is in good health and works out every day. He has managed to shield his gay lifestyle from discovery, as far as he knows. He does not see that it is the firm's business, as long as he does his job. And he has done it well—his evaluations show that. He wonders also what effect it will have on his work as organist and choir director at his local church. This pervasive anxiety makes it difficult to focus his attention on his work. In his close circle of friends, he has voiced his fear of AIDS, and their urging that he has nothing to worry about has not quieted his fears. His worst fears are realized when he attends the testing center to receive the results of the antibody test and is informed that he is HIV positive; there are AIDS virus antibodies in his blood. The counselor informs Bryan that the blood sample will be retested, using a more stringent test, to confirm or invalidate the first result.

Both men are experiencing events which they do not understand and for which they are unprepared. Previously in good health, both are strong individuals with a high degree of need to control their own lives. Each is confronted suddenly with a crisis. For Alan Anderson, it is the unexpected experience of illness and the blow to his self-image. Bryan Bates faces the unknown fears that gather

around the word "AIDS" with deep apprehension. Each man before these events had a clear picture of the future: for Anderson, it was the likelihood of promotion following the excellent response to his report of the New York staff meeting, while Bates had recently received confirmation of his admission to an advanced training course offered by his company. Now, events beyond their control threaten their respective futures. While neither man describes himself as depressed, each exhibits indications of mild depression: sleeplessness, fatigue, and diffused anxiety. Freud had attributed the state of anxiety to the emotional response to a situation of danger. Silvano Arieti, advancing Freud's work, identified anxiety as "the emotional reaction to the expectation or anticipation of danger,"¹ noting that the danger is not necessarily immediate, nor is it always well defined. The threat may be one of actual physical danger, but it may also be a threat to the values and meanings given to one's existence. It is just such threats that both Anderson and Bates are experiencing.

Alan Anderson is not aware of all these aspects of his situation as he lies in the hospital awaiting further tests. He is aware of feeling enervated, and even that listlessness worries him. He is unaccustomed to illness and resents being hospitalized. He should have been able to throw off this infection; he has always been able to do so in the past. In fact, he prided himself on his hardiness. Unnerved by his confinement, his irritability quickly surfaces, first with himself, then with his wife, Barbara. Barbara alternates between attempts to reassure him and impatience at his outbursts.

As Bryan Bates waits in the clinic office for the results of the second test, he is filled with anger. Since the age of nineteen, when he first knew he was gay, he has feared the time when control over his life would slip from his hands and others would determine his fate. God, what will he tell Mom and Dad if he is infected. *Will* he tell them?

The feeling of loss of control complicates the efforts of each man to cope with the sense of threat. Recent researchers have determined that the feeling of being unable to

control one's life, of not having a say over what happens to one, has far-reaching consequences for both physical and mental health. Jerry M. Burger² found that people with a high need for control are more susceptible than others to bouts of depression, particularly when they perceive that they have lost control over events in their lives. His research confirms earlier work by Martin Seligman, who found that people generally feel helpless and hopeless when faced with repeated traumatic events over which they have little control.³ Judith Rodin⁴ has added another dimension to this research. Her work with elderly people suggests that under extreme stress, loss of control triggers a physiological response that can lead to disease. She hypothesizes that stress due to loss of control is related to loss of effectiveness in immune functioning. While research is still at a very early stage, these tentative results seem to indicate a close correlation between perceived threat of loss of control over life decisions and values and impairment of mental and physical coping mechanisms. Just at the moment when Anderson and Bates need all their coping resources, events are combining to reduce their abilities to cope.

Alan Anderson is impatient; the doctor is late for his rounds. He has picked up signals that there is something unusual about his case, but when he asks questions of the nursing staff, they have been evasive. When the doctor enters the room, he pulls up a chair, pauses, then says, "Mr. Anderson, I have some unsettling news for you. There is no gentle way to say this. In trying to locate the source of the infection, we took a blood sample, and I am sure you know we ran a whole range of tests. . . . Well, we found AIDS antibodies in your blood."

Anderson is stunned into silence, then explodes in disbelief. Incoherently, he stammers that could not be possible. He knows how people get AIDS! The lab must have mixed up its samples. They had better take another sample, he wants it walked down to the lab, and they can change the entry in his medical record.

The physician listens to his outburst; he has expected it. He continues: "Mr. Anderson, no one wants to prove it is not

due to the AIDS virus more than I. But we have confirmed the tests. I would like to ask you a few additional questions. I infer you are telling me you are not gay." "Damn right I'm telling you!" The doctor continues: "What I am saying, Mr. Anderson, is that there are other means of contracting the virus. It is possible, for example, to become infected through intercourse with women other than your wife." Then, after a further pause, "There is no doubt about the antibodies, Mr. Anderson." Anderson asks for more time to think it over. "Sure," the doctor answers, and leaves the room.

Anderson finds it hard to sort out the flood of questions and feelings. Barbara will have to be told. How will she react? What will the kids think? God, what will this do to my career? Surely there must be some mistake; he will insist they repeat all the tests. It must have been during the New York staff meeting. He remembers his times with Gloria. . . . But there had been other trips, other Glorias!

Anderson declines the offer to have a hospital staff member counsel with Barbara and him, and, his condition stabilized for the moment, he is discharged with an appointment to meet with his physician a week later. His relationship with Barbara, strained at first, steadily deteriorates. When he informed her, Barbara had responded with disbelief, which quickly turned to anger. Was it worth putting them both at risk? Couldn't he wait till he was home? How could he betray her like this? Would she need to have those tests also? It is difficult to hide the issue from their two sons. Robert, age 15, seems to accuse him—never directly—of wrecking the family. His burden of guilt and self-pity grows.

Bryan Bates knows that it will be difficult to keep the issue to himself. Oh, he knows the tests are confidential—he used another name when registering. But if he begins to develop symptoms, especially those purple spots, and others start asking questions, what will happen then? He has seen too many friends with AIDS not to be afraid. He stands at his desk, rereading his last personnel evaluation, and the attached recommendation that he be admitted to the advanced training course offered in the company's New York offices. Well, that's over. He'll take the course if it is offered to him. But his anger burns again. Why me?

CASE C

Cliff Cassidy has every reason to be proud of his achievements. At 43, he is the youngest member in the boardroom. His record is the envy of many. There has been, he acknowledges to himself, a certain amount of good fortune—he would not call it “luck,” as some did—but it is true that in at least two situations he was in the right place at the right time. In any case, none of all this would have occurred if he had not been adept in capitalizing on what had befallen him. He has applied himself diligently—a word that appears repeatedly in his personnel file—and his dedication and abilities have placed him where he now sits.

His wife shares his achievements, and, with him, enjoys the status and benefits that accrue from his rapid promotion. The daughter of a Wall Street broker, Beth is accustomed to the stresses of corporate life and has not permitted them to disrupt their family life unduly. Their two children, Michael, age 22, and Mary, 19, have been straight-A students all through high school, and Mike graduated cum laude from Notre Dame. Cliff was disappointed that Mike has shown no interest in West Point. He has never raised the issue with Mike, but, in the ways that these things are often resolved in families, he knows that Mike was aware of his hope and would have been angered if the issue had been broached head-on. Mike's choice of two majors, foreign languages and political science, has prepared him for a career with the State Department, and there is little doubt he will be accepted. Mike is due back from a six-month European tour he elected to take as his parents' graduation gift. He took the State Department examination before leaving for Europe, having arranged with their Senator that, if accepted, he will defer the interviews until after his return.

Mike arrives home with a persistent sore throat and a dry cough from which he does not seem to be able to obtain any relief. But it is Mike's physical appearance that worries Cliff. Mike has always been a first-class athlete and, six feet in height, has carried his 200 pounds comfortably. He returns from Europe twenty pounds lighter. A few days later, Mike adds to Cliff's concern by disclosing that he has had a daily problem with diarrhea for four weeks. Cliff immediately insists

that Mike see their doctor, but Mike is unusually resistant to this urging. During the following two days, Mike is alternately irritable and preoccupied, the irritability surfacing each time Cliff inquires if he feels any better. After one outburst, Mike apologizes for his behavior and informs his father there is something they need to talk over.

They walk into the office Cliff maintains at home, and Mike blurts out, "Dad, I have wanted to tell you this for a long time. I am gay. And I am afraid to go to the doctor." Cliff responds in anger, "What do you mean, you're gay? You can't be." Mike replies, "Dad, I am gay. I have known since my freshman year. I didn't tell you because I knew you and Mom would be hurt. You know that Frank went with me to Europe. Well, we have been lovers since my junior year. Now you have to know the rest of the story. Frank became ill while we were in Paris, and he has been diagnosed with AIDS. I don't think I have AIDS. They said in Paris that I am infected, but I wasn't sick then. I have been doing a lot of reading, and it seems I may have AIDS-related complex."

Later that evening, after Mike leaves the house, Cliff and Beth try to make sense out of the shattering situation in which they find themselves. Mary has told them that she knew about Mike's gay lifestyle, but had promised Mike that she would leave it to him to tell their parents when he was ready to do so. She knew he continually deferred that decision and agreed with some ambivalence that they probably would not understand. And, Cliff and Beth are clear, they do not. They do not understand this at all. On top of it all, they are terrified by the revelation that Mike's illness might portend the onset of AIDS. The following morning, on reaching his office, Cliff picks up his phone and dials his pastor. "Pastor, could you come by the house tonight, say, about 7:30 P.M.? There is something rather urgent we need to talk over with you."

Questions for the Pastor

Case A: Alan has not to this point indicated any readiness or wish to seek pastoral care or counseling. When you visited him in hospital, communication was superficial and guarded. Now, Barbara has informed you that Alan has AIDS. She is struggling with her anger with Alan but has

deferred the decision to leave him. What criteria would you use to determine whether or not to intervene with Alan? If you decide to do so, how would you initiate that process? Outline your pastoral counseling plan for the family.

Case B: Bryan has just left your office. He had walked in and informed you bluntly that he is HIV antibody positive. It occurred to you, in the midst of the feelings of shock and dismay, that he expected you would ask for his resignation as organist and choir leader. What went through your mind as you listened to Bryan? How do you plan to resolve your own feelings? What are the proximate and long-term issues raised by Bryan's disclosure? Prepare an outline indicating how you hope to respond to Bryan. Describe the pastoral response to Bryan that you hope will unfold within the congregation.

Case C: What are the key elements of Cliff's situation that you anticipate you will need to address? List the feelings you sense Cliff is experiencing. Imagine that, when you visit the Cassidys tonight, you will be meeting with Beth, Cliff, and Mike. What do you anticipate may be your priorities during that visit? What response would you make to the question, "Where did we go wrong?" How would you respond if Mike were your son? How would you separate these issues from your ministry to Beth and Cliff and to Mike? What information about AIDS and male homosexuality do you need in order to minister to each member of the Cassidy family?

Notes

Chapter 1. AIDS—The Medical Facts

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The American Nurses' Association Code encompasses concerns for "the promotion and restoration of health, the prevention of illness, and the alleviation of suffering." Confidentiality and the updating of knowledge and expertise aid in the nurse's effort to protect a patient and the public from misinformation. See "The American Nurses' Association Code for Nurses," 1, 2, 6–8, 10–11, in Beauchamp and Childress, pp. 333–335.

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AIDS, a Manual for Pastoral Care

Ronald H. Sunderland and Earl E. Shelp

An estimated 1.5 million Americans are infected with the deadly AIDS virus. Not confined to homosexuals or intravenous drug users, this disease threatens millions regardless of their sex, age, race, or geographical location.

Viewing AIDS from a pastoral perspective, the authors of this manual state: "The mushrooming effects of the disease and the emotions of hurt and bewilderment it has stirred will be alleviated only through the efforts of people who meet the challenge with compassion. . . . To neglect the opportunities for ministry generated by AIDS constitutes a failure of discipleship. Neither the individual Christian nor the church as the community of the people of God has any option."

Drs. Sunderland and Shelp designed this brief manual to help pastors, chaplains, and other caregivers who are called upon to engage in a special ministry of compassion to the victims of AIDS and their families and friends as well. They cover the medical facts, the fears that grip people, grief recognition and response, and ethical issues. They also provide cases and a bibliography of additional resource material.

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